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including the right to development**

Human rights defenders working on albinism

Report of the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka-Anne Miti-Drummond

Summary

The present report, submitted in accordance with Human Rights Council resolutions 28/6 and 46/12, covers the work of human rights defenders with albinism and human rights defenders working on albinism in various regions of the world. It also includes information on numerous challenges that are experienced by human rights defenders in their line of work. Reference is made to good practices, and recommendations are made to States and other relevant stakeholders. The Independent Expert intends the present report to provide clarity on a subject that is still relatively new for people with albinism, and to empower them in their work to address the human rights challenges they face.



Introduction

1. The present report of the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka-Anne Miti-Drummond, is submitted pursuant to Human Rights Council resolutions 28/6 and 46/12. The report provides a brief summary of the Independent Expert's activities and also focuses on human rights defenders with albinism and human rights defenders protecting and promoting the rights of persons with albinism.

2. In preparing the report, the Independent Expert sent questionnaires¹ in October and November 2022 to stakeholders including Member States, civil society organizations and non-government stakeholders. She held a series of consultations with stakeholders through virtual interviews – mainly with civil society organizations from Africa, Asia, Europe and South America. She received 39 submissions, some of which came out of the consultations and others which were received in written form.² These submissions have primarily informed the content of the present report.

3. Although there is extensive literature and research on the situation of human rights defenders, there is little information about human rights defenders with albinism and about human rights defenders promoting and protecting the rights of persons with albinism. The present report is aimed at providing a better understanding of the specific challenges that they face, at increasing their visibility and their ties with other human rights defenders and with human rights and civil society organizations, and at identifying best practices and making recommendations to create an enabling environment for their work.

I. Activities of the mandate holder

4. During the reporting period, the Independent Expert engaged in various activities, some of which are highlighted here. In March, she took part in a lecture at the University of Pretoria on contemporary issues regarding albinism. She also made a presentation on the work under this mandate, at Staffordshire University, United Kingdom of Great Britain and Northern Ireland, and took part in a seminar on ending witch-hunts in India. In May, she spoke on witchcraft accusations and ritual attacks against children, at a conference organized by the African Child Policy Forum, in Addis Ababa. In June, she provided a keynote address at a training programme for organizations of persons with albinism, organized by the Centre for Human Rights at the University of Pretoria. In July, she took part in and made a presentation at a conference organized by the National Organization for Albinism and Hypopigmentation, in the United States of America. In August, she advocated for the adoption of the guidelines entitled “Accusations of Witchcraft and Ritual Attacks: Towards Eliminating Harmful Practices and Other Human Rights Violations”, at the Pan-African Parliament. The guidelines were subsequently adopted in November. In the same month, she spoke at the Southern Africa Human Rights Defenders Network conference on the subject of human rights defenders with albinism. Throughout the year, she conducted training for civil society organizations run by persons with albinism – including in December in partnership with the civil society team at the Human Rights Council and Treaty Mechanisms Division of the Office of the United Nations High Commissioner for Human Rights (OHCHR). The Independent Expert engaged with various United Nations offices, including the Office of the United Nations High Commissioner for Refugees, the United Nations Educational, Scientific and Cultural Organization (UNESCO) and the World Health Organization. In September, the Independent Expert undertook an official visit to Madagascar, the report on which is published as an addendum to the present report.³

¹ Office of the United Nations High Commissioner for Human Rights (OHCHR), Call for inputs for the report of the Independent Expert on the enjoyment of human rights by persons with albinism to the Human Rights Council at its fifty-second session, in March 2023, available at <https://www.ohchr.org/en/calls-for-input/2022/call-inputs-report-independent-expert-enjoyment-human-rights-persons-albinism>.

² Submissions were received from the following Member States: Ecuador, Italy, Malaysia, Mauritius, Nigeria and South Africa. The remaining submissions were received from civil society organizations.

³ [A/HRC/52/36/Add.1](#).

II. Definitions

A. Human rights defender

5. “Human rights defender” is a term used to describe a person who, individually or with others, acts to promote or protect human rights in a peaceful manner. There is no specific definition of who is or can be a human rights defender. The Declaration on the Right and Responsibility of Individuals, Groups and Organs of Society to Promote and Protect Universally Recognized Human Rights and Fundamental Freedoms (more commonly known as the Declaration on Human Rights Defenders) refers to “individuals, groups and associations ... contributing to ... the effective elimination of all violations of human rights and fundamental freedoms of peoples and individuals”.⁴

6. According to this broad categorization, a human rights defender can be any person or group working to promote human rights and fundamental freedoms at the local, national or international levels. Defenders can be of any gender, of varying ages, from any part of the world and from all sorts of professional or other backgrounds. Nevertheless, the “standard” required of a human rights defender is a complex issue, and the Declaration on Human Rights Defenders indicates that defenders have responsibilities and rights. These include: (a) the acceptance of the universality of human rights; (b) the defence of human rights regardless of whether human rights defenders are correct in their arguments; and (c) the requirement that actions taken by human rights defenders be peaceful, in order to comply with the Declaration on Human Rights Defenders.⁵

7. According to this definition, any person with albinism or relative of a person with albinism who defends human rights or any person who promotes and protects the rights of persons with albinism is a human rights defender if he or she acts in a peaceful manner and accepts the indivisibility of rights as defined by the Universal Declaration of Human Rights. Human rights defenders with albinism and working on albinism and associations of persons with albinism carry out essential human rights work at the local, national and international levels, including human rights education to raise public awareness about albinism and the needs of persons with albinism, and training of health and education professionals. They contribute to developing laws, policies and programmes related to persons with albinism, which often improves the delivery of their rights to health, education and employment. They also denounce attacks against persons with albinism and hold governments accountable for these violations.

B. Albinism

8. Albinism is a rare, non-contagious, genetically inherited condition which occurs worldwide regardless of ethnicity or gender. It most commonly results in the lack of melanin pigment in the hair, skin and eyes (oculocutaneous albinism), causing vulnerability to sun exposure. Albinism is still profoundly misunderstood, socially and medically. The physical appearance of persons with albinism is often the object of erroneous beliefs and myths influenced by superstition, which foster their marginalization and social exclusion.

9. Persons with albinism are a unique group whose human rights issues have generally gone unnoticed for centuries; the result being deeply engraved stigma, discrimination and violence against them across various countries. The complexity and uniqueness of the albinism condition means that their experiences significantly and simultaneously touch on several human rights issues, which include, but are not limited to, discrimination based on colour; discrimination based on disability; special needs in terms of access to education; the right to the enjoyment of the highest standards of health; and the right to life, which should guarantee persons with albinism protection against harmful traditional practices, violence

⁴ General Assembly resolution 53/144, annex. See the fourth preambular paragraph.

⁵ See <https://www.ohchr.org/en/special-procedures/sr-human-rights-defenders/about-human-rights-defenders#ftn3>.

including killings and ritual attacks, trade in and trafficking of body parts for witchcraft purposes, infanticide and abandonment of children.

III. Normative framework for the protection of human rights defenders

10. The Universal Declaration of Human Rights and the International Covenant on Civil and Political Rights enshrine the fundamental rights and freedoms that are inherent to all human beings, such as the rights to life, humane treatment, freedom of expression, freedom of assembly and association, political participation, equality and non-discrimination, access to justice and judicial guarantees. In the regional frameworks, similar provisions exist in the African Charter on Human and Peoples' Rights, the American Convention on Human Rights and the Convention for the Protection of Human Rights and Fundamental Freedoms (European Convention on Human Rights).

11. In the case of persons with albinism, the protection against discrimination based on disability, colour and gender guaranteed by specific instruments, including the Convention on the Rights of Persons with Disabilities,⁶ the International Convention on the Elimination of All Forms of Racial Discrimination,⁷ the Convention on the Elimination of All Forms of Discrimination against Women⁸ and the Convention on the Rights of the Child,⁹ is of crucial importance. Several regional human rights treaties provide further protections against discrimination. These include the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa, the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa,¹⁰ in which persons with albinism are included specifically as a constituency of persons with disabilities and are therefore protected, the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, the African Charter on the Rights and Welfare of the Child, the Inter-American Convention against Racism, Racial Discrimination and Related Forms of Intolerance, the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities, the Inter-American Convention Against All Forms of Discrimination and Intolerance, and various documents adopted by the European Union, the Organization for Security and Cooperation in Europe and other bodies.¹¹

12. Respect for and protection of these internationally and regionally recognized rights and fundamental freedoms make it possible to defend and promote human rights and, ultimately, to exercise the right to defend them. As noted by the Special Rapporteur on the situation of human rights defenders, they are instrumental to the defence of human rights. The implementation of these rights is a prerequisite for the creation of a safe and enabling environment for human rights defenders in which they can carry out their work.¹²

13. The "defence" of human rights as a right in itself is formally defined in the Declaration on Human Rights Defenders.¹³ In this regard, the Declaration recognizes that "everyone has the right, individually and in association with others, to promote and to strive for the protection and realization of human rights and fundamental freedoms at the national and

⁶ See art. 5.

⁷ See art. 1.

⁸ See art. 11.

⁹ See art. 2.

¹⁰ Both the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa and the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa have not yet come into force, however.

¹¹ See <https://www.equalrightstrust.org/document-types/regional-instruments?page=4>.

¹² A/74/159, para. 25; and A/73/215, para. 19.

¹³ The Declaration on Human Rights Defenders is not, in itself, a legally binding instrument. However, it contains a series of principles and rights that are based on human rights standards enshrined in other international instruments that are legally binding, such as the International Covenant on Civil and Political Rights. Moreover, the adoption of the Declaration by the General Assembly by consensus represents a firm commitment by States to its implementation.

international levels”.¹⁴ The Declaration also acknowledges the key role of human rights defenders in the realization of the human rights enshrined in the Universal Declaration of Human Rights and legally binding treaties and in the international human rights system.¹⁵

14. In addition, the Declaration on Human Rights Defenders reaffirms other already existing rights and fundamental freedoms, and frames them in a way relevant to the legitimate work of human rights defenders: (a) the right to meet or assemble peacefully;¹⁶ (b) the right to know, seek, obtain, receive and hold information about human rights and fundamental freedoms and freely to publish, impart or disseminate to others views, information and knowledge;¹⁷ (c) the right to submit to governmental bodies and agencies concerned with public affairs criticism and proposals for improving their functioning;¹⁸ and (d) the right to participate in peaceful activities against violations of human rights and fundamental freedoms, with the State to take all necessary measures to ensure the protection of everyone against any violence, threats, retaliation, de facto or de jure adverse discrimination, pressure or any other arbitrary action as a consequence of his or her legitimate exercise of those rights.¹⁹

15. States have a primary responsibility and duty to protect, promote and implement all human rights and fundamental freedoms. With respect to human rights defenders, this duty includes creating an enabling environment for their work by establishing a legal, institutional and administrative framework conducive to their activities. As stated by the Special Representative of the Secretary-General on the situation of human rights defenders, “adequate protection requires a comprehensive and transversal policy from Governments to establish an appropriate environment where the legitimacy of the work of human rights defenders is respected, the legal framework is in line with the Declaration’s provisions, and those taking adverse actions against defenders can be brought to justice”.²⁰

16. In addition, States’ primary responsibility for protecting individuals, including human rights defenders, under their jurisdiction requires that they refrain from violating the rights of defenders and act with due diligence to prevent, investigate and punish any violation of rights by State and non-State actors,²¹ as reiterated by various human rights bodies, including the Human Rights Committee²² and the Inter-American Commission on Human Rights.²³ States’ duty to protect also includes the responsibility to cooperate with regional and international mandates,²⁴ and mechanisms for the protection of human rights defenders,²⁵ by

¹⁴ See arts. 1 and 13.

¹⁵ See art. 18.

¹⁶ See art. 5.

¹⁷ See art. 6.

¹⁸ See art. 8.

¹⁹ See art. 12.

²⁰ E/CN.4/2006/95, para. 45.

²¹ See the preamble to the Declaration on Human Rights Defenders, and arts. 2, 9 and 12.

²² For example, in its general comment No. 36 (2018), on the right to life, the Human Rights Committee states that the duty to protect the right to life requires States parties to take special measures of protection for persons in situations of vulnerability whose lives have been placed at particular risk by specific threats or pre-existing patterns of violence, including human rights defenders. The Committee likewise states that article 6 also reinforces the obligations of States parties under the Covenant and the Optional Protocol to protect individuals against reprisals for promoting and striving to protect and realize human rights, including through cooperation or communication with the Committee, and that States parties must take the necessary measures to respond to death threats and to provide adequate protection to human rights defenders, including the creation and maintenance of a safe and enabling environment for defending human rights.

²³ See, for example, Inter-American Commission on Human Rights, “Towards effective integral protection policies for human rights defenders”, OEA/Ser.L/V/II. Doc. 207, 29 December 2017, para. 9.

²⁴ The Special Rapporteur on the situation of human rights defenders; the Special Rapporteur on Human Rights Defenders and Focal Point on Reprisals in Africa; the Rapporteurship on Human Rights Defenders and Justice Operators, of the Inter-American Commission on Human Rights; and the Council of Europe Commissioner for Human Rights.

²⁵ For example, the Human Rights Defenders Unit of the Inter-American Commission on Human Rights, and the focal point for human rights defenders of the Office for Democratic Institutions and Human Rights.

reporting measures being taken to protect human rights defenders in their own and other countries and by implementing the interim measures provided by those international²⁶ and regional human rights mechanisms.²⁷

17. Although States bear the primary responsibility for protecting human rights defenders, the Declaration on Human Rights Defenders is addressed to everyone. In article 10 of the Declaration, it is stated that no one shall participate, by act or by failure to act where required, in violating human rights and fundamental freedoms. In addition, the Declaration reaffirms the responsibility of everyone not to violate the rights of others, which encompasses the responsibility of non-State actors to respect the rights of human rights defenders – in the preamble as well as in articles 11, 12 (3) and 19.

18. The essential role of human rights defenders and the need to promote their work has also been recognized in regional systems for the protection of human rights in Africa, the Americas and Europe. The Grand Bay Declaration and Plan of Action on Human Rights in Africa, adopted by the African Union in 1999, calls on African Governments to take appropriate steps to implement the Declaration on Human Rights Defenders.²⁸ This was supplemented by the Cotonou Declaration on Strengthening and Expanding the Protection of All Human Rights Defenders in Africa.²⁹ In Europe, the Declaration of the Committee of Ministers on Council of Europe Action to Improve the Protection of Human Rights Defenders and Promote Their Activities, of 2008,³⁰ details States' obligations and lists some examples of protection measures that could be taken. The revised European Union Guidelines on Human Rights Defenders,³¹ adopted by the European Council in 2008, suggest practical measures for European Union member States to support and protect human rights defenders. They further highlight the role that States have in protecting human rights defenders in other countries and providing access to financial support. The inter-American human rights system has also stressed the work of human rights defenders as fundamental for the implementation of human rights. Based on this obligation, the Inter-American Commission on Human Rights and the Inter-American Court of Human Rights have referred to the importance of adopting an integral protection policy³² or public policy of protection³³ for human rights defenders that promotes respect for their rights and fosters a safe and secure environment in which they can perform their work without reprisals.

19. Most human rights defenders working on issues related to albinism are persons with albinism or relatives of persons with albinism. Their main areas of work include protecting and promoting the right to life and physical integrity, and the rights to non-discrimination, education, employment and the highest attainable standard of health. They also carry out human rights education programmes and campaigns to raise awareness among families of children with albinism, civil society, government authorities, and health and education professionals about albinism and about the rights and specific needs of persons with albinism.

²⁶ Some United Nations treaty bodies provide for interim measures, in order to avoid possible irreparable damage to the victims of the alleged violation, among them human rights defenders. These include rule 94 of the rules of procedure of the Human Rights Committee, and rule 114 of the rules of procedure of the Committee against Torture. Article 5 of the Optional Protocol to the International Covenant on Economic, Social and Cultural Rights also provides for interim measures in exceptional circumstances.

²⁷ For example, the precautionary and provisional measures granted by the Inter-American Commission on Human Rights and the Inter-American Court of Human Rights, respectively, or the provisional measures granted by the African Commission on Human and Peoples' Rights.

²⁸ Available at <https://www.achpr.org/legalinstruments/detail?id=44>.

²⁹ See <https://www.achpr.org/news/viewdetail?id=31>.

³⁰ See https://search.coe.int/cm/Pages/result_details.aspx?ObjectID=09000016805d3e52.

³¹ See https://eeas.europa.eu/headquarters/headquarters-homepage_en/3958/EU%20Guidelines%20on%20Human%20Rights%20Defenders.

³² Inter-American Commission on Human Rights, "Towards effective integral protection policies for human rights defenders", OEA/Ser.L/V/II. Doc. 207, 29 December 2017.

³³ Inter-American Court of Human Rights, *Luna López v. Honduras*. Merits, reparations and costs. Judgment of 10 October 2013. Series C, No. 269; and Inter-American Court of Human Rights, *Human Rights Defender et al. v. Guatemala*. Preliminary objections, merits, reparations and costs. Judgment of 28 August 2014. Series C, No. 283, para. 142.

IV. Challenges of human rights work

A. Lack of visibility and recognition as human rights defenders

20. Many albinism associations and activists do not identify themselves as human rights defenders, and States consider them support groups rather than as human rights defenders. Some might choose not to use the term “human rights defender” for fear of reprisals, to avoid the negative connotations that some Governments attach to human rights defenders or to differentiate themselves from other defenders reporting attacks against persons with albinism who are exposed to threats and intimidation. However, as the Special Rapporteur on the situation of human rights defenders notes, effective protection of defenders ultimately starts with their identification and self-identification as human rights defenders. Without being perceived by others or themselves as such, they may not be aware of their rights as defenders, may not seek support from peers or support networks and may not receive protection from the State, civil society and the international community.³⁴

21. Although their work is focused on fighting discrimination and promoting the rights of persons with albinism, many defenders do not realize that their work constitutes human rights work and are not always aware of international human rights legislation and standards that guarantee their right to defend human rights, or of the international, regional and national legislation and mechanisms they can use to enhance their visibility and increase their protection. Most human rights defenders with albinism and working on albinism do not refer to human rights standards in their line of work, due to lack of knowledge regarding these standards.

B. Lack of resources, capacity and training

22. The lack of understanding about albinism, and of its recognition as a human rights concern, restricts the opportunities to obtain funding, as donors consider that albinism is not a priority issue or that it may be an issue that is already covered by other organizations working on the rights of persons with disabilities. As a result, albinism associations often have to compete for scarce resources, and this, in some cases, may hamper necessary collaboration among them. Human rights defenders working on albinism often cite the lack of resources and of access to funding as one of the main issues jeopardizing their work.

23. Many human rights defenders working on albinism operate as small entities, carrying out activities at great personal financial cost, and often having to balance income-generating work with their work as human rights defenders, putting further pressure on their time, social and family life, and resources. Many report a significant strain on their mental and emotional health, having to deal with the complex needs of persons with albinism (from guaranteeing protection and accountability for physical attacks to accessing specialized health care and adequate accommodation in schools and the workplace, as well as, in some cases, supporting asylum-seekers fleeing persecution), without the capacity or the resources, or the knowledge about how to do this. Others indicate that further strain is put on them because the authorities expect them to carry out activities that should be the State’s responsibilities – from providing statistical data on albinism and the number of people affected, to drawing up protocols and organizing training programmes for health professionals and teachers, and even recruiting volunteer dermatologists to treat persons with albinism for skin conditions in rural areas.

24. Some defenders indicate that the lack of resources and capacity means that they are not able to tackle all the issues affecting persons with albinism, and often, organizations focus on the areas where their members have some expertise or where funding is available, instead of adopting a more strategic, comprehensive and integrated approach that takes into account the indivisibility and interdependency of the human rights of persons with albinism. As noted by one human rights defender with albinism: “Most human rights defenders depend on their personal experiences and stories. Still, they lack professional training, and the use of appropriate advocacy tools to advance their work.” There are also concerns that financial

³⁴ [A/HRC/31/55](#), paras. 41–42.

constraints may make some human rights defenders, especially those dealing with sensitive issues such as attacks against persons with albinism, more prone to self-censorship and to censorship by the authorities.

C. Security challenges

25. In countries where persons with albinism face human rights violations related to accusations of witchcraft and ritual attacks, human rights defenders with albinism are also exposed to further security risks. However, albinism associations indicate that they lack adequate training on security, and protocols to assess the particular security risk they face. Even when defenders are aware of the security measures necessary, applying them represents an additional challenge to their human rights work. As noted by human rights defenders with albinism: “Most of us are financially incapable of taking security measures like installing security systems at our homes or going home by car instead of walking.” “We use public transport most of the time ... and are exposed to so many security risks, especially at off-peak times. Our eyesight gives us a challenge to spot the danger and be able to respond swiftly to protect ourselves in those situations.” A woman defender detailed to the Independent Expert the extensive precautions she must take when travelling, due to fear of being attacked along the way just because of her status as a person with albinism. These include sending her pigmented husband to buy the ticket, so that people do not know a person with albinism will be travelling in the vehicle, having her luggage loaded ahead of her, only boarding the bus once she receives information that it is about to depart, and not leaving the bus, even on long journeys, for food or bathroom stops.

D. Lack of cooperation and coordination with the wider human rights movement

26. Over the years, human rights defenders with albinism and human rights defenders working on albinism have developed solid national and international networks and strong cooperation. However, associations of persons with albinism rarely work with other civil society and non-governmental organizations and are not always visible or included in other human rights and civil society networks, including those protecting and promoting the rights of persons with disabilities and of human rights defenders. This is partly due to the lack of awareness and understanding about albinism, which is not considered a human rights issue or recognized as a disability in some countries. In some cases, this has complicated and delayed the process of registering human rights organizations focused on the rights of persons with albinism as disability organizations. In other instances, albinism associations and human rights defenders cite the limited resources and the need for more capacity to attend and participate in these meetings. As noted by a prominent human rights defender with albinism: “Being part of a wider network of NGOs is useful and makes me feel protected.”³⁵

V. Risks and threats relating to human rights defender work

27. In most countries, defending human rights is a risky activity. Additionally, the space for civil society has increasingly been reduced, as Governments have imposed restrictive legislation to curtail civil society activities and funding and have adopted measures to significantly restrict the freedoms of expression, peaceful assembly, association and movement.³⁶ This is also the reality for human rights defenders with albinism and human rights defenders promoting and protecting the rights of persons with albinism, particularly in Africa.

28. Threats against human rights defenders with albinism and working on albinism include violations of their right to life and physical integrity and their right to justice. In addition, since many defenders working on the human rights of marginalized groups are

³⁵ Jake Epelle, Nigerian human rights defender and founder of The Albino Foundation.

³⁶ A/HRC/31/55, para. 28.

themselves from marginalized groups, they also face discrimination on that basis. They endure intersecting forms of discrimination because of their colour and disability, and gender discrimination, in the case of women defenders, as they are often perceived as challenging traditional notions of family and gender roles in society.

A. Threats and intimidation

29. In countries where physical attacks against persons with albinism occur, the work of human rights defenders with albinism and working on albinism puts them at personal risk, as they threaten the interests of powerful groups. Human rights defenders reporting kidnappings, attacks and killings of persons with albinism and seeking justice for the survivors or their relatives have been subjected to death threats and attempted kidnappings, and forced to flee their homes out of fear for their safety and the safety of their families. The Independent Expert has received reports of at least nine defenders receiving death threats in the past five years for denouncing violations of the right to life and to physical integrity of persons with albinism and seeking justice for these. The threats are allegedly perpetrated by those involved in the attacks, including traditional healers and powerful groups and individuals. None of these death threats is known to have been investigated and none of the defenders has received any protection from the State. At least three defenders had to flee their homes, and in some cases, their countries, out of fear for their lives and for the safety of their families.

30. In one of the latest examples of threats and intimidation against human rights defenders with albinism known to the Independent Expert, a defender who had reported to the police the kidnapping of a woman with albinism informed the Independent Expert that in November 2021, after the police had released the three alleged perpetrators, he had received a phone call from one of them warning him that the other two alleged assailants were planning to kill him. He reported the incident to the police, but to date he has received no protection and has had to leave his family home and go into hiding. In November 2022, he was followed by a car without number plates after attending a meeting with civil society organizations. The two men in the car tried to force him to get inside the vehicle but fled the scene when some bystanders intervened. In September 2022, at least four members of albinism groups were threatened following a demonstration by disability rights groups in another country. A member of the albinism group received a call in which the threats were uttered against the human rights defenders with albinism. In a recording received by the Independent Expert, the person carrying out the threats stated: “Those [persons with albinism] of yours, I will sell them one by one ... Do you understand? ... Those [persons with albinism] of yours are business. You even know that just a toe is millions.”

31. The Independent Expert has also received reports that indicate that some civil society organizations that report attacks against persons with albinism have refrained from publishing information on further incidents after being subjected to pressure by Governments. For example, in its submission, the African Albinism Network stated: “A coalition of civil society organizations that issued a press release on a case of an attack against a person with albinism (in 2021) appeared to have received some blowback from the government, causing them some hesitation in issuing a similar release after another attack was reported in 2022.”

32. Human rights defenders who demand protection of the rights to education and the highest attainable standard of health for persons with albinism have been intimidated and discredited by being accused of receiving foreign funds and have been threatened with investigations into their organizations’ accounts. Some defenders also mention being subjected to harassment by government authorities and accused of tarnishing their country’s reputation after cooperating with the United Nations or with international and regional organizations to promote and defend human rights. Other human rights defenders with albinism have mentioned that they fear reprisals from perpetrators of attacks against persons with albinism. “When we speak publicly to demystify these notions, they think we are destroying their business in the body parts of persons with albinism.” Yet another human rights defender with albinism told the Independent Expert of an incident where he received death threats while on television talking about the rights of persons with albinism. The same

threats were transmitted to the producer of the show. All these threats have in common the intent to intimidate and silence defenders.

33. Human rights defenders working on albinism do not always have adequate knowledge about security and the measures they can take to guarantee their physical, digital and psychosocial well-being. In particular, human rights defenders with albinism receive insufficient support to address the toll on their mental, emotional and psychological well-being from documenting severe human rights violations, particularly considering that those violations are motivated by prejudice and discrimination based on their condition. Those who have been threatened in the past and have had to relocate to ensure their safety indicate that they acquired a better understanding about security issues after receiving some training or advice from international human rights organizations such as Amnesty International, or cooperating with other human rights defenders in documenting human rights violations.

B. Stigmatization and discrimination

34. Human rights defenders with albinism face the same intersecting discrimination as other persons with albinism. In many countries, they are discriminated against because of their colour and disability. Human rights defenders report being called derogatory names, being abused in the media and on social media, being prevented from accessing communities to carry out human rights education programmes and being disregarded or considered less capable than their peers because of their disability. In the words of a woman human rights defender recently interviewed by the Independent Expert: “When I attend meetings and conferences, people never expect me to be a spokesperson. They always assume that the other human rights defenders without albinism will be doing the talking.” Human rights defenders state that this discrimination affects their self-esteem and their confidence to speak out on matters affecting them to influence policy.

35. Albinism associations and human rights defenders in the global North have also highlighted a lack of genuine consultation and inclusion of persons with albinism in discussions, by health-care providers. They have stated that they do not acknowledge the expertise of leaders of albinism associations and do not give them much, or any, room in the decision-making process with regard to how the health-care system is designed to address the needs of persons with albinism.

C. Adequate accommodation at work

36. Some human rights defenders with albinism who work on issues not related to albinism indicate that the human rights and civil society organizations where they are employed are unable or unwilling to provide adequate accommodation or carry out adequate security risk assessments that take into account the specific risks they may face because of their condition. Reasonable accommodation at work is essential to ensuring that persons with albinism can enjoy the right to work on an equal basis with others. Examples of reasonable accommodation include the provision of large computer screens or double screens, as well as other assistive devices and technology; ensuring that persons with albinism are not seated in direct sunlight; and providing appropriate and flexible working hours and arrangements to reduce exposure to the sun and to attacks for persons with albinism. According to the information submitted to the Independent Expert, human rights defenders constantly have to remind their employers to ensure that their accommodation on field missions is safe and adequate for their specific needs. Due to the difficulties that persons with albinism face in finding employment, human rights defenders with albinism are reluctant to discuss these needs for fear of not being considered for the position, even when, in some cases, their employers use the fact that they are members of the staff to demonstrate their inclusivity, for example with donors.

D. Challenges and risks faced by women human rights defenders

37. Women with albinism face intersecting forms of discrimination because of their disability, colour and gender, particularly in patriarchal societies where their work is seen as challenging social and cultural norms. As noted by a high-profile woman human rights defender with albinism who has filed a complaint for discrimination against a colleague: “Women with disabilities have to fight even more to have our voices heard.” One albinism association raised concerns that cyberbullying tended to be directed more against women. Women defenders further report being undermined and questioned regarding their ability and competence to do the work and being “shut down during discussions or ignored on their points, only for a man to repeat the same point later and be heard”. In some countries, even in forums for discussing gender issues, women with albinism are not always able to raise the issues affecting them, as male defenders speak on behalf of women.

38. Women human rights defenders also report cases of sexual harassment, including by peers, a lack of mechanisms to file complaints and a lack of adequate gender-sensitive security protocols. In some countries, women human rights defenders with albinism are at a higher risk of sexual harassment and violence due to fetishes, myths and misbeliefs and to the prevalent myths that sexual intercourse with women with albinism can cure HIV and can confer good luck. In addition, some albinism associations in Africa have indicated that the fact that most of them are newly established groups led by persons with albinism with limited resources makes women more vulnerable to sexual exploitation.

39. Women with children with albinism who advocate for their rights face exclusion and isolation from their communities and abandonment and violence by their partners. They also experience loss of income or income-generated activities, both because of the fear of leaving their children alone at home or school and therefore vulnerable to attacks, or because their communities do not think they have the capacity to carry out such activities. The negative stereotypes that lead to attitudinal barriers in response to albinism tend to be driven by the presumption that persons with albinism and mothers of children with albinism are “a null unit of production in the community”.³⁷ As a result, many experience dire poverty.

E. Good practices³⁸

40. The challenges that human rights defenders working on albinism face, in terms of limited capacity, resources and visibility, the discrimination and threats they endure and the psychological impact that these have on their well-being, highlight the need to build their capacity, develop networks between these human rights defenders and other human rights organizations working on other rights, and strengthen their protection in a holistic way, considering their physical security as well as their “economic security, political security, environmental security, digital security and psychosocial well-being”.³⁹

VI. Capacity-building

41. Some albinism associations have developed initiatives to build the capacity of human rights defenders with albinism and working on albinism, in particular by strengthening their knowledge and awareness about human rights and the legal basis to defend those rights, about the international, regional and national legislation that guarantees human rights and about the

³⁷ I. Ero and others, “Women human rights defenders: a case of activism of mothers of children with albinism in Tanzania”, M. Rioux and R. Addlakha, eds., *Handbook of Critical Disability Studies in a Globalizing World*, p. 15.

³⁸ A good practice in protecting human rights defenders is a practice that contributes to the full respect of their rights and strengthens their security, including by mitigating the risks they face, addressing threats and building support for their work (see [A/HRC/31/55](#)).

³⁹ Protection practices should focus on strengthening the security of defenders in a holistic manner. Security should not be defined as physical security alone, but should be understood as encompassing multiple dimensions, including economic security, political security, environmental security, digital security and psychosocial well-being (see [A/HRC/31/55](#)).

mechanisms they can use to protect them. For example, the organization Standing Voice has developed resources and training for human rights defenders with albinism and has made significant efforts to equip persons with albinism and those who surround them with the tools they need to defend and demand their rights, articulate their needs and claim full participation in society, including by strengthening the capacity of women human rights defenders impacted by albinism. Women have established support groups and engaged relevant duty-bearers in discussions about their needs and rights and have embarked on programmes of community outreach to raise awareness of albinism and human rights, interacting directly with service providers, government officials, civil society leaders and communities and providing psychosocial support to other women impacted by albinism.

42. The African Albinism Network has also developed training programmes on human rights for human rights defenders with albinism, and offers them opportunities to put that training into practice in various national, regional and international forums, such as national human rights commissions, the African Commission on Human and Peoples' Rights, and the Human Rights Council and its mechanisms. The African Albinism Network aims to build the capacity of the recently created regional forum on albinism as a core group of advocates and, eventually, trainers of trainers. Others, such as the Centre for Human Rights at the University of Pretoria, Amnesty International, Human Rights Watch, some United Nations country offices and UNESCO, as well as the mandate of the Independent Expert, have also contributed to building the human rights capacity of associations of persons with albinism by providing training to understand albinism within the human rights framework. More needs to be done in this area, particularly by raising awareness about the Declaration on Human Rights Defenders among human rights defenders with albinism.

43. The information received by the Independent Expert indicates that defenders with albinism and working on albinism would benefit from improving their skills in monitoring and documenting violations, including on issues such as informed consent and avoiding jeopardizing the safety and security of survivors. Some international human rights organizations, such as Amnesty International, have offered training to human rights defenders with albinism on documenting human rights violations. For example, Amnesty International and the African Albinism Network have developed a mentorship relationship that has provided the latter with access to a vast network of civil society organizations and the possibility to consult on how to deal with issues that may be new to them, such as government threats or reprisals, and some particular kinds of allegations of human rights violations. Other human rights defenders with albinism have mentioned the positive impact of mentorship programmes with well-established human rights organizations. More needs to be done to include human rights defenders with albinism and working on albinism in such training programmes, in order to ensure defenders' safety and the safety and well-being of the survivors of human rights violations whom they are supporting.

44. Some organizations have produced manuals that can be useful in integrating security into the work of human rights defenders and to help them address their protection needs more systematically. For example, Frontline Defenders issued a protection manual for human rights defenders,⁴⁰ which was updated by Protection International.⁴¹ The manual is aimed at providing human rights defenders with knowledge and tools for understanding and assessing risks and threats in order to develop effective security and protection strategies and plans. It is supplemented by the Workbook on Security: Practical Steps for Human Rights Defenders at Risk.⁴²

45. The Organization for Security and Cooperation in Europe (OSCE) has also produced guidelines on the protection of human rights defenders.⁴³ Other organizations have developed

⁴⁰ Available at https://www.frontlinedefenders.org/sites/default/files/protection_manual_-_english.pdf.

⁴¹ See <https://www.protectioninternational.org/wp-content/uploads/2012/04/Protection-Manual-3rd-Edition.pdf>.

⁴² Available at https://www.frontlinedefenders.org/sites/default/files/workbook_eng_master.pdf.

⁴³ Available at <https://www.osce.org/odihr/guidelines-on-the-protection-of-human-rights-defenders?download=true>.

similar manuals specific to certain professions,⁴⁴ as well as in relation to digital and online protection.⁴⁵ There are also some regional networks of human rights defenders that provide resources and support to human rights defenders.⁴⁶ While many of these give special focus to different groups of human rights defenders, including women human rights defenders and LGBTI human rights defenders, none appear to have a particular focus on human rights defenders with albinism or working on albinism. Some international human rights organizations, such as Amnesty, have offered individual ad hoc training to some human rights defenders with albinism who have endured threats. Also, the organization CBM has issued guidelines on security measures for persons with albinism,⁴⁷ which include some steps to be taken when attending meetings which can also be useful for defenders. In addition, the non-profit organization The Engine Room is providing training and support to the Ugandan albinism organization, Albinism Umbrella, on data security, responsible data collection and data protection policy.⁴⁸

46. In addition to these positive initiatives, more needs to be done to develop and organize training programmes and security manuals specifically directed to human rights defenders with albinism and working on albinism that address their particular security needs in a holistic manner and to address the intersectionality of factors that affect their security (gender, colour and disability).

A. Building and supporting networks

47. Formal and informal networks connecting defenders and supporters are crucial to protection. Through these networks, human rights defenders share information, pool resources, coordinate responses and offer psychosocial support. The extent to which defenders are connected, recognized, respected and knowledgeable affects their access to and enjoyment of protection initiatives. Defenders who are more remote and isolated, whose work is delegitimized or stigmatized, or who have less knowledge about strategies, tactics and resources, are less likely to benefit from protection initiatives and will be more vulnerable to insecurity. Networks of defenders and their allies facilitate the provision of support, heighten recognition and strengthen solidarity.⁴⁹

48. Albinism associations have come together and built strong national and international networks. For example, in 2020, a group of 27 regional and special delegates of different organizations and groups working on albinism elected seven people to conduct a pilot programme to create the Global Albinism Alliance at the end of 2022. Among other things, the Global Albinism Alliance aims to facilitate knowledge and skills development, collaboration and sharing of information among organizations working on albinism, and to represent and advocate on behalf of albinism associations worldwide. In South Africa, the National Albinism Task Force, established in 2019, serves as a forum for all persons with albinism to consult on how the National Action Plan on Albinism will be implemented. Many albinism associations have also developed strong cooperation with civil society organizations

⁴⁴ See, for example, the International Bar Association toolkit on lawyers at risk, available from https://www.ibanet.org/Human_Rights_Institute/Toolkit-on-Lawyers-at-Risk-project.

⁴⁵ See the Digital Defenders Partnership, at <https://www.digitaldefenders.org/>; Civil Rights Defenders, *Security Guidelines for Human Rights Defenders*, available at <https://crd.org/wp-content/uploads/2020/01/Security-guidelines-for-HRDs1.pdf>; and Amnesty International, “Digital surveillance threats for 2020”, available at <https://www.amnesty.org/en/latest/news/2020/01/digital-surveillance-threats-for-2020/>.

⁴⁶ For example, the Pan-African Human Rights Defenders Network, with a membership of subregional networks – see <https://africandefenders.org/about/>; the EU-LAT Network – see https://eulatnetwork.org/about-eu-lat-network/#who_we_are; the Euro-Mediterranean Foundation of Support to Human Rights Defenders – see <http://emhrf.org/>; and the Asian Forum for Human Rights and Development (Forum Asia) – see <https://www.forum-asia.org/>.

⁴⁷ See <https://www.cbm.de/dam/jcr:8252b21c-b36a-4f10-8b85-86f7fc7bfd90/security-guideline-for-people-with-albinismcbm.pdf>.

⁴⁸ The Engine Room, “Meet our new matchbox partners”, available at <https://www.theengineroom.org/meet-our-new-matchbox-partners/>; and information received from the organization.

⁴⁹ See A/HRC/31/55.

promoting and protecting the rights of persons with disabilities. However, more must be done to include human rights defenders in broader human rights networks. Cooperation between defenders within the same context will foster understanding, support and capacity-building, even if they focus on different rights.

B. Strengthening the protection of human rights defenders

49. Various reports of the Special Rapporteur on the situation of human rights defenders provide measures that States should follow in protecting human rights defenders.⁵⁰ These reports recommend that States protect human rights defenders by: (a) creating an enabling environment for the work of human rights defenders; (b) ensuring accountability for violations against human rights defenders; and (c) cooperating with regional and international bodies in the protection of human rights defenders in their own and other countries. All such interventions need to take into account, address and include the specific challenges of persons with albinism as human rights defenders. Strategies to protect persons with albinism as human rights defenders should involve them in the development process in order to ensure understanding of their specific challenges.

C. Creating an enabling environment for human rights defenders

50. The environment in which defenders operate must support the exercise of the human rights that are fundamental to both their activities and their safety. An enabling environment for defenders is one in which their work has the broad support of society and in which the institutions and processes of government ensure that they can operate free from hindrance, reprisals and insecurity, ensuring, among other things, the right to take part in the conduct of public affairs, the freedom to seek, receive and impart information, and equal access to justice, including to an effective remedy.

51. A way in which States can provide an enabling environment for human rights defenders working on albinism is to facilitate and support the granting of permits or visas to allow entry into countries where respite can be sought and security and protection provided. Visas and multiple-entry visas are widely regarded as a vital element of a comprehensive security strategy.⁵¹ These good practices have been adopted by Ireland through its Humanitarian Visa System for Human Rights Defenders, in which a fast-track approach is applied to the processing of applications for recognized human rights defenders for short stays due to temporary safety issues and for respite.⁵² Spain also has a one-year residential visa for human rights defenders through the Spanish Programme for Support and Protection of Human Rights Defenders, aimed at providing temporary shelter.

52. Increasing the visibility of human rights defenders with albinism and of human rights defenders protecting and promoting the rights of persons with albinism, and raising awareness of and support for their activities and situation, can serve to lower their risk of attacks if the State takes action to highlight this activism as something positive that contributes to strengthening human rights protection and the rule of law. Human rights education on the rights of persons with albinism, on the importance of the work of human rights defenders on albinism, and on threats that they face, enables society to appreciate and to show solidarity with their work, and can serve a protective function.

53. Albinism associations have developed and implemented multiple human rights education programmes targeting the general public and health and education professionals. These have raised awareness about albinism and the rights of persons with albinism, and have also contributed to raising the profile of human rights defenders and creating links between

⁵⁰ See, for example, [A/HRC/13/22](#), [A/HRC/25/55](#) and [A/HRC/31/55](#), and Human Rights Council resolution 22/6.

⁵¹ See <https://protectdefenders.eu/international-civil-society-urge-european-union-actors-to-guarantee-eu-visa-human-rights-defenders/>.

⁵² See question 7 at <https://www.ohchr.org/sites/default/files/Documents/Issues/Defenders/LargeScale/Govts/Ireland.pdf>.

them, professionals and government authorities. For example, in October 2022, the network of albinism associations in Latin America held an albinism congress for health professionals in the region. In the same month, the Pierre Fabre Foundation held the third African Dermatology Conference, in Côte d'Ivoire, bringing together over a hundred participants from more than ten countries. The conference reviewed the progress made in the training of health professionals and the prevention of social and health risks for persons with albinism. In November 2022, the Global Albinism Alliance held the International Scientific Conference on Albinism, a global forum for health-care providers, researchers, leaders of albinism organizations, and individuals interested in albinism to meet, share ideas and experiences, and discuss strategies to advance the knowledge of albinism in order to tackle the health challenges faced by persons with albinism and their relatives in all regions of the world.

54. Human rights awards have also been developed as a way of creating a positive image of human rights defenders. Awards for defenders are a means of drawing attention to their important work and the risks that they face. Some of these awards provide financial benefits to help human rights defenders in their work. While many of these are provided by the private sector, the State can support such initiatives financially or by partnering with the private sector. In a positive step, some of these awards have recently nominated human rights defenders with albinism or working on albinism. In December 2021, the President of the Nigerian Albino Foundation was awarded the Franco-German Human Rights and Rule of Law Prize. In 2022, the Prime Minister of the United Kingdom awarded the Commonwealth Point of Light award to John Chiti, a leading advocate for persons with albinism and founder of the Albinism Foundation of Zambia. The award recognizes outstanding individual volunteers who are making a change in their community.

D. Developing and strengthening legislation, policies and practices

55. Strategies to create an enabling environment require national institutions, such as national human rights institutions and parliamentary human rights committees, to respond to cases of intimidation and attacks against human rights defenders, including through inquiries and making recommendations to relevant institutions for appropriate steps to be taken. Some countries, for example Brazil, Colombia and Mexico, have developed specific protection mechanisms for monitoring and reporting threats and attacks against human rights defenders, coordinating the response of the State, and making recommendations to reform laws and policies that conflict with the rights of defenders or that place them at risk. In order to support efforts by such bodies to engage with human rights defenders working on albinism and to ensure increased understanding of their specific risks and support needs, Amnesty International and the Open Society Initiative for Southern Africa have developed a manual to assist national human rights institutions to carry out their functions in relation to the promotion and protection of the enjoyment of all human rights of persons with albinism.⁵³ The manual is specifically designed for national human rights institutions based in the Southern Africa region, that is to say, the countries of the Southern African Development Community, however the principles contained in it are equally applicable to other regions.

56. Enacting laws and policies for the protection of human rights defenders with appropriate remedies is another step towards preventing attacks. Brazil, Burkina Faso, Colombia, Côte d'Ivoire, Guatemala, Honduras, Mali, Mexico and Peru reportedly have some form of legislation that is aimed at protecting human rights defenders.⁵⁴ The International Service for Human Rights has produced a "Model National Law on the Recognition and Protection of Human Rights Defenders", which States can use in developing similar laws.⁵⁵ Individuals working on albinism should be recognized as human rights defenders in the context of these laws. Positive examples in this regard include the legislation promoting and protecting the rights of persons with albinism in Guinea, which recognizes

⁵³ Amnesty International, *Promoting and Protecting the Rights of Persons with Albinism: A Manual for National Human Rights Institutions*, available at <https://www.amnesty.org/en/wp-content/uploads/2021/07/AFR0338792021ENGLISH.pdf>.

⁵⁴ [A/74/159](#), para. 61; and [A/HRC/31/55](#), para. 91.

⁵⁵ Available at <https://www.ishr.ch/news/model-law>.

the role of organizations of persons with albinism and the need for the State to work with them. In Ghana, the revised Disability Act allows organizations of persons with disabilities, including albinism, and individuals with a disability, to carry out and promote the work of these organizations.⁵⁶

57. In the African region, Governments have implemented positive initiatives to promote the work of human rights defenders and protect persons with albinism. For example, the Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (2021–2031) includes steps which aim to deepen the overall capacity-building of organizations representing persons with albinism and support the participation and leadership of persons with albinism in public settings. Similar measures have been included in the national action plans in Malawi, aimed at the mainstreaming and empowerment of persons with albinism; South Africa, seeking to strengthen their advocacy tools; and Uganda, where self-advocacy of persons with albinism is enshrined as a fundamental principle of the national action plan.⁵⁷ In Mali, a project has been launched on protecting the human rights and promoting the economic empowerment of persons with albinism, supported by the justice and health ministries, the police force, various religious leaders and traditional healers. In Zambia, the appointment of an influential human rights defender with albinism to the police commission has offered human rights defenders with albinism a sense of security and protection, as they now have a contact to reach out to when they are in danger. In addition, they are able to influence police protection policies that address their specific needs.

58. In South Africa, the albinism communities identified security threats emanating from traditional healers, by whom they felt targeted. The Department of Justice and Constitutional Development held, in 2019, a dialogue on ritual femicide, to discuss the victimization of female persons with albinism because of baseless spiritual grounds and ritual beliefs, including the belief as regards *muti* about the use of body parts giving traditional healers or spiritual leaders who believe in it extraordinary powers. The Office of the Presidency also established a presidential working group in 2015 for persons with disabilities, which included representation from the Albinism Society of South Africa. Prior to this, the Ekurhuleni Declaration on the Rights of Persons with Albinism, of 2013, was developed and adopted by a conference to address the myriad challenges experienced by the albinism community.

E. Regional and international support

59. The duty to protect human rights defenders lies first and foremost with the State. However, the international community plays an essential role in supporting States in fulfilling their responsibilities, by supporting the development of robust policies and guidelines, monitoring and responding to the situation of defenders and providing flexible funding for their protection.

60. The OSCE Guidelines on the Protection of Human Rights Defenders support partnerships between Governments and defenders aimed at addressing the challenges of the latter. The European Union Guidelines on Human Rights Defenders set out regional policy objectives and practical initiatives for the European Union and its member States in support of defenders worldwide. The European Union Guidelines call upon diplomatic entities to monitor the status of human rights defenders through regular contact with them, by receiving them in missions and by visiting their places of work; to support their work publicly through the media; to react to cases of threats; to raise specific cases with third governments; to provide emergency visas and offers of temporary accommodation for human rights defenders in danger; and to provide access to financial support. The European Union Guidelines are complemented by the European Instrument for Democracy and Human Rights, which provides financial assistance to organizations supporting the work of defenders. The European Union Guidelines have provided a foundation for developing national policies and

⁵⁶ Persons with Disability Amendment Bill, 2020, sect. 56 (4).

⁵⁷ Ministry of Gender, Labour and Social Development, National Action Plan for Persons with Albinism 2020–2025, executive summary, p. 7, available at <https://albinismumbrella.org/wp-content/uploads/2022/06/NAPPWA-Executive-Summary.pdf>.

plans of action in, for example, Finland, Ireland and the Netherlands. Other States, such as Norway and Switzerland, have also adopted national guidelines for supporting defenders. Such guidelines must be disseminated widely, so that defenders with albinism and working on albinism can be aware of how to engage with relevant actors concerning their protection, and States must allocate the necessary resources for their implementation.

61. The Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (2021–2031) includes measures to strengthen the capacity of organizations representing persons with albinism, including by promoting and facilitating their establishment and supporting them at the local and national levels by providing organizational development training. The Inter-American Commission on Human Rights has developed an integral protection policy for human rights defenders,⁵⁸ which details States' obligations. These include, among other things, the adoption of an appropriate legal framework and short-term and long-term measures to allow human rights defenders to freely pursue their activities; the gathering and maintaining of accurate statistics on violence against defenders; the training of public officials; official recognition of the role and importance of the work of defenders; and the carrying out of serious and effective investigations into any human rights violations against them.

62. While albinism organizations are generally not included in the work of regional and international human rights defenders' organizations, there is growing recognition of the need to integrate them. In November 2022, the Southern Africa Human Rights Defenders Network hosted a regional conference of human rights defenders. No human rights defenders with albinism attended this conference, however there were human rights defenders working on albinism in attendance. In addition, the Independent Expert addressed the conference, regarding the need for more inclusion of persons with albinism and attention to their concerns in such gatherings.

VII. Conclusions and recommendations

63. **The present report offers some information about the situation of human rights defenders with albinism and human rights defenders protecting and promoting the rights of persons with albinism. Although there is a need for additional research on this issue, the report provides some insights into some of the challenges and threats that human rights defenders with albinism and working on albinism face. The main challenges include the lack of resources and capacity, and of knowledge about human rights, including their right to defend human rights, as well as the limited visibility and links with other human rights organizations and networks. Threats against human rights defenders with albinism and working on albinism include violations of their right not to be discriminated against on the basis of their colour, disability and gender, of their right to life and physical integrity and of their right to justice.**

64. **The Independent Expert makes the following recommendations to States:**

(a) **Guarantee that national legislation and policies provide a framework for the protection and promotion of the work of human rights defenders, including human rights defenders with albinism and human rights defenders protecting and promoting the rights of persons with albinism, in line with international and regional human rights standards, including the Declaration on Human Rights Defenders.**

(b) **Develop well-funded national protection programmes for human rights defenders that take into account the specific risks and needs of human rights defenders with albinism and human rights defenders promoting and protecting the rights of persons with albinism. Strategies to protect human rights defenders with albinism and human rights defenders protecting and promoting the rights of persons with albinism should involve them in the development process in order to ensure an understanding of the specific challenges and risks that they face.**

⁵⁸ Inter-American Commission on Human Rights, "Towards effective integral protection policies for human rights defenders", OEA/Ser.L/V/II. Doc. 207, 29 December 2017.

(c) Guarantee appropriate investigations into threats and attacks against human rights defenders, including those with albinism and those working on albinism, and ensure that a clear message is sent that such threats and intimidations will not be tolerated, including through public statements in support of the human rights defenders and by bringing perpetrators of such acts to justice. Human rights defenders should also have access to appropriate interim protection measures in cases of threat, and to remedies for attacks, including adequate compensation.

(d) Proactively gather information about the situation of human rights defenders with albinism and working on albinism.

(e) Cooperate with international and regional mechanisms for the protection of human rights defenders by providing information on the threats faced by and the protection measures for human rights defenders working on albinism.

(f) Develop human rights education programmes that raise awareness about the Declaration on Human Rights Defenders and the positive contribution of human rights defenders, including defenders with albinism and working on albinism.

(g) Develop human rights training programmes for government authorities and health and education professionals that include information about albinism and the rights of persons with albinism, including their right to defend human rights under the Declaration on Human Rights Defenders.

(h) Increase the visibility and recognition of human rights defenders with albinism and human rights defenders protecting and promoting the rights of persons with albinism by proactively including them in consultations and discussions with civil society and human rights organizations.

(i) Implement a policy that can provide a facilitated procedure for granting visas to human rights defenders who are at risk of threats and reprisals, into countries that can provide an environment of security and respite.

65. In her recommendations to other stakeholders, the Independent Expert:

(a) Urges non-governmental organizations to develop and strengthen their relationship and collaboration with human rights defenders with albinism and human rights defenders working on the promotion and protection of the rights of persons with albinism, in order to share information and expertise, pool resources, coordinate efforts and offer psychosocial support;

(b) Urges organizations working on the protection of human rights defenders to acquaint themselves with the work of human rights defenders with albinism and human rights defenders working on albinism and with their specific needs, and to proactively incorporate them into their programmes of work and training initiatives, in particular those focused on the right to defend human rights under the Declaration on Human Rights Defenders, on the international, regional and national mechanisms that defenders can use to boost their visibility and increase their protection, and on the protocols and measures that they can apply to address security in a holistic manner;

(c) Urges the United Nations and intergovernmental regional organizations to request that States provide information about the situation of human rights defenders with albinism and human rights defenders working on albinism and that they ensure that the policies and guidelines for the protection of human rights defenders include measures for the protection of human rights defenders with albinism and working on albinism, in consultation with those defenders;

(d) Urges diplomatic entities to include human rights defenders with albinism and working on albinism in their programmes for support to human rights defenders, including their implementation of the European Union Guidelines on Human Rights Defenders;

(e) Urges donors, particularly those funding non-governmental organizations working on the rights of persons with disabilities, to ensure that their policies are flexible enough to include persons with albinism and human rights defenders with albinism and working on albinism;

(f) Urges organizations, companies and other entities providing human rights awards to actively include human rights defenders working on albinism in the criteria for nominations.
